



# SPINAL COURIER

**SPINAL CORD**  
COMMISSION

Vol. 8, No. 3

April 1997

## New Commission Members Join ASCC

Governor Huckabee recently appointed two new members to the Arkansas Spinal Cord Commission, the five person consumer board that oversees ASCC.

**Deanna Van Hook** was appointed in January. Deanna has lived with paraplegia since her spinal cord injury in a motor vehicle crash in 1984. She is a graduate of



Newly appointed ASCC Commission Member Deanna Van Hook with Tasha, her service dog.

University of Texas at Arlington with a degree in Marketing. She presently works in the Institutional Advancement Department at UAMS. Deanna, her husband Tom (a medical student at UAMS) and her service dog Tasha live in Little Rock. In her free time, Deanna, a former Ms. Wheelchair USA and world-class markswoman, serves as a youth group leader at her church. Deanna replaces Grover Evans, who resigned from the Commission when he assumed a position with another state agency, and will serve until 1999.

**James Miller** was appointed by the Governor in February. A native of Harrison, Jim sustained his injury which resulted in paraplegia in 1977, while he was living in New York City, when his store was robbed and he was shot. Jim returned to Harrison where he now lives. He is very involved in collecting antiques, particularly cut glass, of which he and his family have an extensive collection. Jim is also very



Jim Miller of Harrison, AR was recently appointed by Gov. Huckabee to the AR Spinal Cord Commission.

interested in health, utilizing alternative health options such as acupuncture and reflexology to deal with chronic pain. Jim replaces Sloan Lessley whose term expired. Jim will serve until 2007.

We look forward to working with both Deanna and Jim as they assume their roles on the Commission. ☺

## Conference . . . What Conference ?

Usually around this time, you receive information on the ASCC annual "Living With Spinal Cord Injury" Conference. You may be wondering what's up this year. Well, after seven conferences, we are taking a short break. No state-wide conference is planned for 1997. Instead, we will be coordinating at least two mini-conferences around the state, probably in North and in South Arkansas, to give some of you outside of Central

Arkansas a chance to attend without long travel. Dates and locations for these mini-conferences are being finalized and you should hear more details in the July *Spinal Courier*.

We are already at work planning an even bigger and better 1998 conference. "Living With Spinal Cord Injuries: Strategies for a New Century" is scheduled for Spring 1998 in Little Rock. It will be a two day regional conference.

The Commission has received a \$25,000 grant from the Education and Training Foundation of the Paralyzed Veterans of America to assist us with this conference, including assistance for bringing in national speakers as well as funding for consumer participant travel stipends to help defray attendance costs and allow more people to attend. You will be hearing more about the conference as plans are finalized.

## SPINAL COURIER

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Sheila Galbraith Bronfman, Chair  
Russell Patton  
Sandra Turner  
Deanna Van Hook  
James Miller

The Arkansas Spinal Cord Commission  
does not discriminate on the basis of race,  
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of services.

## BUCKLE UP!

### With Thanks

ASCC accepts tax deductible donations. The generosity of the many individuals and families who over the years have made memorial donations is greatly appreciated. Contributions are used to assist our clients through purchases of equipment and educational resources.

If you would like to make a contribution, please contact the Commission at **(501) 296-1788 / (800) 459-1517 / TDD (501) 296-1794** or send your donation to:

AR Spinal Cord Commission  
1501 North University, Suite 470  
Little Rock, AR 72207

#### *Donations this quarter from:*

Glendon Graham  
Quitman High School FHA Club

*In Honor of Sheila Bronfman*  
Linda Shearer

*In Memory of Dr. Allen Hill*  
Terry and John Penn  
Dr. and Mrs. Bruce Brown  
Allan Meier  
Dr. and Mrs. Mike Bell  
Mrs. Billy Turpin  
Vesta Brantley  
Vanessa Baird  
Merchants & Farmers Bank of W. Helena

*In Memory of Dr. Al Davis*  
Mr. and Mrs. David Garrett  
Mary and Kelly Cohoon  
Lisa Perks

## SPINAL COURIER Letters

Questions • Suggestions • Directions • Answers

### Beware of Promotions!

Dear Editor:

Recently I received a phone call touting Millwood Landing Resort. I was told at the time that they were on Lake Millwood just out of Ashdown, AR. The promotional people also told me that the facilities *were handicapped accessible*, including at least one cabin. **Beware!**

Upon arrival, I discovered to my dismay, that the facilities were not on Millwood Lake and the **only**

thing I was shown that was wheelchair accessible was their clubhouse/restaurant.

If you are wheelchair confined and get an offer to visit these people, I personally would not recommend it!

*Jimmy DeBruin*  
*El Dorado, AR*

\* Editor's Note: ASCC does not check out promotions aimed at spinal cord disabled persons. The above is the writer's experience and opinion.

### From The Director

It's a beautiful Spring afternoon, far too nice to be indoors, but here I sit at my computer, pondering what another new Spring will bring. It looks to me like it will bring more change. I am always intrigued by change. Though it makes me grit my teeth and dig in my heels sometimes, for the most part, change is good. But, change is hard. We have two new Commission members here at ASCC, two very capable, interesting people with new ideas and perspectives. I look forward to working with them, but, at the same time, I will miss the two members who are leaving, one of whom I've known since I came to Arkansas. Change is good, change is hard.

We are also making some changes in the way we provide services. Those individuals who have all the resources and support that they need and do not feel a need for visits from ASCC Case Managers will move to a new independent status. We're excited about this, it reinforces our belief that people with disabilities can and do live independent lives, and it will free up our Case Managers to help those folks who are in need of help. But, we'll miss our visits with some of you, who we learned from when we visited and who helped us remember what independence is about. Change is good, change is hard.

So many things are changing these days (can we really believe it will be easy to get car tags?) that it's hard to tell the good from the hard some days. But we keep trying, accepting the changes, some with gritted teeth and others with open arms. It would be a pretty boring world without change, wouldn't it?!!

*Cheryl L. Vines*

# Some SSI Recipients Face Redetermination

The federal Welfare Reform Act of 1996 included provisions which changed the definition of disability for State Supplemental Income (SSI) recipients who are children. Since 1990, disability in children has been evaluated for SSI using a process known as Individualized Functional Assessment (IFA) which assessed the effect of the disability on a child's ability to function.

The new Welfare Reform Act ordered the Social Security Administration to discontinue the use of IFA and to develop a new definition of disability for children. These new definitions state that an impairment is a disability if it causes "marked and severe functional limitations." These limitations will be tested using definitions of "listing level severity for functional limitations."

What does all this mean? In Arkansas, it means that over 7,000 children with disabilities will undergo redetermination utilizing the new definitions over the next six months. Some will not meet the new requirements and will lose SSI benefits. According to the Social Security Administration, the majority of children up for redetermination will be those whose disability is based on behavioral disorders and less severe learning disabilities. Though we would not expect spinal cord disabilities such as spina bifida or spinal cord injury to fit under these, there may be some cases who are required to undergo redetermination.

What should you do? If you receive notification that your child is required to undergo re-evaluation, by all means, go to the appointment. In preparation for the appointment, gather all of the recent medical records that you

can find regarding your child's disability. Contact the child's physician to obtain additional records and information that you can provide to the evaluator (**take copies of records or ask that copies be made**). The evaluator should provide you with information on how to appeal the decision at the time of the reevaluation. If he or she does not, **ask for the information**. If your child is denied SSI based on the reevaluation, appeal the decision. If you have questions, contact the Arkansas Disability Determination for Social Security at **682-3030**. &

## ICAN Offers Revolving Loan Fund



The Technology Equipment Revolving Loan Fund for assistive technology became a reality in Arkansas due to the release of \$125,000 in funds. ICAN will contribute an additional \$30,000 to the fund to help finance the loans. ICAN (Increasing Capabilities Access Network) a program of AR Rehabilitation Services, is the federally funded technology project for Arkansas which was created by the Technology-Related Assistance for Individuals with Disabilities Act.

The loan fund was created by the Arkansas Legislature to enable Arkansans with disabilities, family members and businesses to purchase equipment or modifications necessary to increase independence and accessibility or to enhance productivity. The fund provides an avenue to help fill the gaps for often expensive technology needs that are not provided by insurance or other sources. The fund is "revolving," meaning that future loans will be made from repaid loans.

The fund is administered by a nine member committee appointed by

the Governor. The makeup of the committee is mandated to include at least five members with disabilities and certain professional designations listed below. The members are Robert Burnett, Sr. V.P. Commercial Loans, Boatman's National Bank of AR; Russell H. Patton, III, CPA; Bobby Simpson, Commissioner of AR Rehabilitation Services; Harold Williams, AR Council for the Blind, a disability-related consumer organization; Sherry Cardell; Jeff Davis, Jr.; James D. Eakin; Forrest Michael Long; and Ronald D. Wheeler.

Consideration of loan applications will tentatively begin in late spring or early summer. Members are particularly concerned about the issues and barriers encountered by individuals who use assistive technology, and how loan fund policy can best address these needs. ICAN needs more information from consumers about the existing needs that will be impacted by the loan fund.

For more information about the loan fund, please call ICAN at **(501) 666-8868**. &

## Scholarships For College



The Spina Bifida Association has two scholarships available for students with spina bifida. One is given by the local Spina Bifida Association and the other is through the national Spina Bifida Association. Applications for both may be requested by calling **851-3351**.

# Alternatives for Adults with Physical Disabilities Waiver Program

The State of Arkansas has received the approval of the Health Care Financing Administration to operate a Medicaid 2176 Home and Community Based Waiver Program for physically disabled adults between the ages of 21 and 64. To qualify for the Alternatives for Adults with Physical Disabilities Waiver Program, individuals must be receiving SSI and qualify for nursing facility intermediate level of care. The cost of maintaining an individual in the community can not exceed the cost of institutionalization.

The services to be offered through the Alternatives

Program include Environmental Adaptations, Attendant Care, Extended State Plan Durable Medical Equipment and Extended State Plan Personal Care. Slated for implementation July 1, 1997, the three year Alternatives Program is designed to serve 200 clients the first year; increasing by 100 clients each of the following years. The Division of Aging and Adult Services will have administrative responsibility for this program.

As additional information regarding applications for the Waiver Program becomes available, ASCC Case Managers will be notified. &

## New Status 66

Beginning April 1, 1997, ASCC implemented a new status client code. ASCC uses status codes to group clients according to the extent of services provided by their Case Managers. The new status code, "Status 66," will include those clients who have attained a high level of independence, have the resources they need and do not need ongoing case management services.

Status 66 clients will not receive regular contact from their Case Managers, but will continue to receive information about ASCC activities and may contact their Case Manager at any time that they want or need services.

ASCC is committed to improving the independence level of each client and this new status code reflects this goal. If you have any questions regarding Status 66, contact your ASCC Case Manager.

## Get that Job! Check with HIRE

HIRE, Inc. can help you get that job you want. The first goal of HIRE (Helping Individuals Receive Employment) is to obtain employment for persons

who are physically and mentally disabled. Funded by AR Rehabilitation Services, a grant through the United Way, donations and fund raisers, HIRE has proved successful in its mission. "We're only seven years old, but our hire success rate is 95%," stated HIRE Director Jane Newman.



HIRE helped ASCC client Johnnie Hubbert get his job at the North Little Rock Olive Garden where he serves as a host and assists in food preparation.

HIRE's main role is matching the needs of business with the skills of individuals with disabilities. Staff members evaluate each job candidate to find out his or her career potential and match the candidate's abilities with potential employers' needs. When all of the persons involved agree that a proper match has been made, a HIRE staff member goes on the job site to learn the requirements of the job. The HIRE staff member (a "job coach") will then train the new employee and monitor his progress in the position.

The job coach will provide any additional help or training that might be required to help the

employee. This might include the use of public transportation to get to and from work, help with wardrobe selection, time management or simply some well-timed words of encouragement. HIRE job coaches are also available to provide post-training support, counsel or assistance should the employee's job description change.

If you would like more information or an application, please contact:

HIRE, Inc.  
5919 "H" Street  
Little Rock, AR 72205  
(501) 666-4473

# Sleep Apnea and SCI

By Shirley McCluer, M.D., ASCC Medical Director

Some of you may remember that I wrote a brief article a year ago (Jan. '96) about sleep apnea. Since then I have learned more about it from personal experience as well as hearing many stories from others who have it, and I think it is important enough to report on again.

Despite many years of curiosity and study, we still do not understand very much about sleep, except that it is necessary for life and anything that disturbs sleep can have serious consequences.

**What is sleep apnea?** Apnea means not breathing. Sleep apnea refers to periods during sleep when no air moves through either the nose or mouth for at least ten seconds. More than five such episodes per hour are considered significant.

**What complications or symptoms can it cause?** Symptoms can include morning headache, fatigue, daytime sleepiness, memory problems, restless sleep, irritability, personality changes, high blood pressure, heart attack, stroke and even death.

People with sleep apnea are 2-5 times more likely to have an automobile accident because of falling asleep while driving. However, some people with severe sleep apnea may not be aware of any symptoms.

**Who is at risk?** In the general population sleep apnea is seen more commonly in middle-aged men (especially if 20-30 pounds overweight), and post-menopausal women. In addition, recent articles in the medical literature suggest that persons with neurological diseases, including spinal cord injury (SCI), polio and multiple sclerosis, are at particular

risk for this problem, so it is important for you to discuss it with your doctor if you suspect that you may have sleep apnea.

**What causes sleep apnea?** There are many recognized causes, but the study of this condition is fairly new and there is still much that is poorly understood about it. There are two basic types and persons with SCI can have either type, or even a combination of both.

■ **Obstructive apnea** - This is the most common type. An effort is made to take a breath, but no air moves because something is blocking the air passage. This blockage can be anywhere from the tip of the nose to the throat. Individuals who snore usually have this type. The usual cause of the obstruction is relaxation of the tongue while sleeping on the back, causing the back of the tongue to block the air passage. Muscle relaxants may increase the chances of this happening.

*... recent articles in the medical literature suggest that persons with neurological diseases, including spinal cord injury (SCI), polio and multiple sclerosis, are at particular risk for this problem . . .*

■ **Central apnea** - In this type, the person makes no effort to breathe. The fault is in the respiratory center of the brain which fails to stimulate breathing for a variety of reasons. This is more commonly associated with aging and with persons with neurological disorders, including SCI. This is also the most likely cause of Sudden Infant Death Syndrome (SIDS).

**What can be done?** Several simple measures may be helpful in mild cases of sleep apnea, such as:



- Avoid alcohol within two hours of bedtime. Alcohol depresses breathing and makes apneas more frequent and more severe.
- Avoid sleeping pills - they also depress breathing.
- Take all medications with care. Medications prescribed for spasticity, headaches, anxiety, depression and other common complaints can affect sleep and breathing.
- Sleep on one side instead of on the back.
- Lose any excess weight.
- Medications to relieve congestion of the nose may be helpful in reducing snoring, but they may aggravate high blood pressure.
- Use a room humidifier.

**How is it diagnosed?** If sleep apnea is suspected, there is a simple screening test that your doctor can order. It can be done in your own home, does not involve any needle sticks and is not expensive. A small device (called a *blood oximeter*) is taped to your finger or your ear lobe. It records your blood oxygen level and pulse rate while you sleep. The results are analyzed in a computer. If this test confirms that you have a problem, you may need a more extensive diagnostic workup before appropriate treatment can be started.

**Who should be evaluated?** Consult a physician if you, or  
*Continued on page 7 - see Sleep Apnea*

# Wheelchair Keeps Client Safe in March Tornado !

Many *Spinal Courier* readers know that a wheelchair can help make life more livable after a traumatic event, but here is an instance of a wheelchair actually saving a person's life **during** a traumatic event. The devastating storms that twisted through Arkansas on March 1, 1997, hit Saline county resident and 15 year ASCC client Pam Gann, who has paraplegia, especially hard.

"I never really took tornado warnings very seriously before this happened," says Pam. "You know there have been many times when the sirens would go off and my husband and I would go get in

the middle of the house or in the closet for ten minutes until the sirens quit. Then it'd be all over. I thought this was just like all the other times."

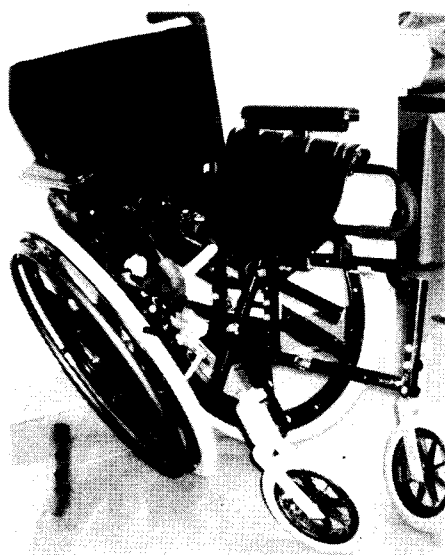
This wasn't like all the other times, though. Pam and her husband Carl situated themselves in the closet to wait for the sirens to quit. Pam says that she felt the air pressure drop dramatically, then heard metal ripping. The next thing she knew, she was flying through the air. She estimates that she and her husband were thrown over a hundred feet! This is where the wheelchair comes into play. Pam landed

sitting upright in her chair. The impact was tremendous, breaking the frame of the two-year-old Quickie II wheelchair in one place and bending it in several others. One of the mag wheels broke as well (those of you with these practically indestructible mag wheels on your wheelchair know how much force it would take to break one!).

Pam and Carl were pretty bruised and banged up, but fortunately none of their injuries was life threatening. "That wheelchair probably saved my life!" declares Pam. One thing is clear, if she had taken the full impact that the chair obviously took, she would have had more serious injuries.

The Ganns must now begin the slow, painful process of rebuilding their lives. Their home was totally destroyed and their cars were heavily damaged. Fortunately, they have insurance to start to address these losses. They are also lucky to have Sunrise Medical's regional representative, Bob Swiney, to help replace her life-saving wheelchair. Within four days of the tragedy, Bob had committed himself to getting Pam mobile again. Quickie Designs is replacing her wheelchair, so that Pam can pay attention to other, more pressing matters. Barbara King, from United Medical in Little Rock, coordinated the fitting and ordering of Pam's new wheelchair.

Pam eagerly anticipated the arrival of her new Quickie chair after having to spend several weeks in an old "clunker" wheelchair. Now, with her new chair, who knows what adventures she will encounter in it. Hopefully, they will be of a happier variety than this most recent one! Best wishes to Pam and her family as they begin to heal, both physically and psychologically, from the effects of the tornado. ♪



The old wheelchair that saved Pam from injury during the tornado.



Safe and happy in her new Quickie wheelchair, Pam is ready to move on.

## ASCC Wheelchair Maintenance Training Sessions Scheduled

The Arkansas Spinal Cord Commission (ASCC) will be having **FREE** Wheelchair Maintenance Training sessions in Magnolia, Pine Bluff and Batesville during the month of May. These trainings are for ASCC clients and family members who are interested in learning how to fix their wheelchair. Those clients who attend will receive a **maintenance**

**manual, Quickie tool kit** and a set of **new tires and tubes** to take home. Take advantage of the opportunity to gain knowledge and get hands-on experience working on your wheelchair!

These trainings will cover **manual wheelchairs only**. For more information, call John Gould at **1-800-459-1517** or **296-1784**. ♪

# Ashish Bhakta -- Science Fair Winner !

ASCC client Ashish Bhakta, a 17-year-old senior who lives with spina bifida, won first place in the Gerontology category at Hall High School in February. As a result, he got to enter his project in the Regional competition March 8 at UAMS, where he received an Honorable Mention. Ashish, who plans to be a doctor, said he chose the gerontology category because this was the first year it had been offered and "new things interest me." Plus, he was curious about whether or not the aging process could be slowed.

Ashish chose to study fruitflies for one month to determine if different kinds of diets affected their lifespans. Ashish divided the flies he obtained from UAMS into four groups:

- Group A was his control group and there was no variation in the diet he gave them.
- Group B was given food with a 50% reduction in yeast which was replaced with cornmeal.
- Group C was given food with a 50% reduction in sugar which was replaced with cornmeal.

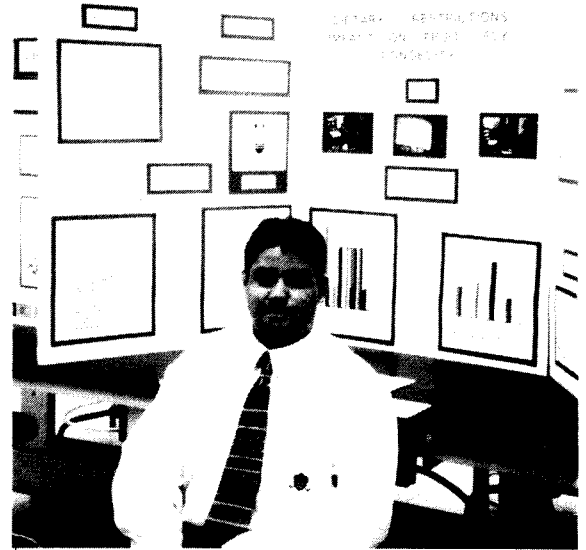
- Group D was given food with a 50% reduction in cornmeal which was replaced with yeast.

Ashish found that the fruitflies in Group C died first. There was little difference in the lifespans of the others. "People today are very concerned about aging and many 'so called miracle creams' are tried with expectations of slowing the aging process," said Ashish. He concluded that a healthy diet will pay you back in more ways than any synthetic product available in the marketplace ever will. "You will not only look better outside, but will feel better inside as well," Ashish noted.

Ashish is an active member of the Jr. Rollin'

Razorbacks and has also participated in competitive wheelchair road racing.

Congratulations to Ashish on his excellent science fair project! &



Ashish with his prize-winning science fair exhibit on fruitfly diet and longevity at Hall High.

## Sleep Apnea

*Continued from page 5*

someone you know, suspect sleep apnea from the above description, especially if someone who sleeps in your vicinity complains that you snore, or says that you stop breathing for a few seconds or a minute while you are sleeping.

In summary, sleep is essential for good physical and mental health and anything that interferes with sleep on a regular basis can have serious consequences. Sleep apnea has been recognized in recent years as a significant cause of sleep disturbance.

Further information about sleep apnea can be requested from the ASCC Educational and Resource Center by calling **296-1792** or **1-800-459-1517**. &

## Farewell to Good Friends

ASCC bade farewell to two of our VISTA volunteers this Spring.

Karen Schmidt, who served three years as our VISTA Education and Resource Coordinator, completed her service in February. During her tenure, Karen was integral in the development of the Commission's Education and Resource Center on SCI. She chaired our Resource Review Committee, developed training manuals, reorganized our resource files and trained staff and users to our resource database. All that was while she sent our resources to those who requested them and handled dissemination of the *Take Control* interactive education CD! Karen's many contributions will be used by ASCC staff and clients for many years to come and are greatly appreciated.

Jim Averitt, our VISTA Equipment Recycling Center Coordinator, completes his two year service

in April. Jim has also filled an integral role at the Commission, coordinating the acquisition, refurbishing and loan of usable durable medical equipment by ASCC clients. During his tenure our former "loan closet" has grown to an Equipment Recycling Center (ERC) in its own workshop. He has coordinated many repairs and made deliveries of equipment to clients in need all over our state, often heading out before dawn with a load of equipment and making stops in several counties before returning at dusk. Jim has also established a database for tracking ERC equipment that will help monitor utilization of equipment on loan.

Karen and Jim have made great contributions to ASCC and the individuals we serve. The Commission Members and Staff extend our sincere appreciation to them and wish them the best in their new endeavors. &

# Spina Bifida Camp

Spring is here . . . what does this mean?

Mention Camp Aldersgate to any child who has been there and you'll get an earful: swimming, parties, cookouts, boating and more. Camp not only provides a wide range of scheduled activities, but it provides a growing experience for the child and parent as well.

The dates for the Spina Bifida Camp this year are **June 8-13** for ages 6 through 11 and **June 22-27** for ages 12 through 16. Camp is open to young ASCC clients with spina bifida and other spinal cord disabilities. All camp buildings are wheelchair accessible and air conditioned. Twenty-four hour medical coverage is provided and all campers receive one-on-one supervision by trained counselors and volunteers.

Application forms, which have been mailed to prospective campers, must be **returned by May 15, 1997**. Since camp selection is based on a "first come, first served" basis, it will be best to return your child's application as soon as possible. If your child does not receive a camp application by mail, please call Betty Massey, ASCC Camp Coordinator, at **(501) 296-1788**.

ASCC is sponsoring these two-week long sessions in cooperation with MedCamps of Arkansas and Camp Aldersgate. ♡

## Calendar of Upcoming Events

### Batesville Spring Fishing Derby

**Saturday, May 17th, from 9:00 am to 2:00 pm** at **Lyon College, Bryan Lake** in Batesville. Lunch will be served and prizes awarded. For more information, contact ASCC Case Manager Charles Crowson at **(501) 793-4153** (voice) / **793-4224** (tdd)



### 1997 PVA National Bass Trail

- *Second Annual Texas Roundup Bass Tournament*  
Lake Ray Roberts, Denton, Texas  
**May 30 - June 1, 1997**  
For more information or to register as an angler, call **(214) 276-5252**
- *Fourth Annual Lake Eufaula Bass Championship*  
Lake Eufaula, Checotah, Oklahoma  
**September 19-21, 1997**  
Contact: Bill Lawson at **(405) 256-6327** or **(800) 321-5041**
- *Third Annual Southeast Bass Tournament*  
Clarks Hill Lake, Augusta, Georgia  
**October 24-26, 1997**  
Contact: Tony Barriga at **(706) 796-6301**

*To have activities announced in the July '97 issue of Spinal Courier call the co-editors at 501-296-1784 by June 27, 1997.*

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